PVRi

Project Coordinator

Recruitment pack

Pulmonary Vascular Research Institute

About PVRI

PVRI is a small charity with a global reach. Our aim is to reduce the global burden of Pulmonary Vascular Disease (PVD) with a particular focus on Pulmonary Hypertension (PH) – a life-threatening and life-limiting condition that affects millions worldwide.

PH can lead to heart damage and trigger symptoms like breathlessness, chest pain, poor growth, and severe difficulties exercising and carrying out normal daily tasks. Diagnosis and care aren't readily available in many parts of the world, and even when it is, PH treatment can itself be challenging and life-changing. Although it's estimated that PH affects 1% of the global population, it isn't widely recognised or well-understood.

To change that, we bring together a fantastic network of energetic and committed PH doctors, academics, regulators, patients, and industry partners. Together we're identifying and addressing the key challenges in global PH, educating the global workforce, and encouraging research. In practical terms, we:

- host international scientific conferences
- produce the only open-access peer-reviewed PH journal, Pulmonary Circulation
- run webinars and e-learning featuring the latest in PVD research
- raise awareness of PH and health inequalities, and advocate for better access to diagnosis, care and treatment - nationally and internationally
- bring our members and professional networks together into working forums:
    - **The Innovative Drug Development Initiative (IDDI):** eight multidisciplinary workstreams working to solve the challenges in PVD research and speed the development of new treatments
    - **Specialty Task Forces:** groups working to advance understanding and improve practice in specific clinical areas of PH
    - **Regional Task Forces:** groups working in-country to address the key regional and national challenges in PH.

We are a London-based registered charity and limited company, governed by an international Board of Trustees and supported by a new Scientific and Medical Advisory Council.

Our small, friendly staff team comprises our CEO Karen, Head of Comms Debs, Marketing Officer Emily, Admin Manager Katie, Operations Manager (currently recruiting), and Project Coordinator Sarah, who is moving away and will sadly leave us shortly. The team is supported by our freelance Finance Manager Steph. We work a flexible hybrid model with office space in Work.Life, close to London Bridge and Borough Market.

In terms of our values, we're open, inclusive and easy to engage with, and we're ambitious for ourselves and for the global PVD community.

About the role

The main focus of the role is to support the work of our forums:

- Innovative Drug Development Initiative (IDDI)
- Specialty Task Forces
- Regional Task Forces

Most of the Coordinator's time is spent supporting our IDDI Workstreams. These usually have two Co-Chairs, one from academia or clinical practice and the other from industry. The groups vary in size from just a handful of people to 20+. Some groups hold regular formal monthly meetings, and others meet ad hoc and infrequently; some are very self-sufficient, and others rely strongly on the Project Coordinator for support. An IDDI Leadership Team of four key global PH players provides guidance and coordination, and the Project Coordinator will work closely with this team and provide support for their meetings.

Our Specialty and Regional Task Forces work in a similar way to the IDDI Workstreams and have similar professional memberships, although not always including pharma partners. Some Task Forces are extremely active, others less so, but all are driven by global leaders in the field of PH.

The majority of workgroup members already work long hours in their own roles, so administrative and project support from the Project Coordinator is vital. Because the groups work at different paces and different ways, the Coordinator's workflow can be a little uneven and unpredictable, so the postholder needs to be able to juggle competing priorities, and negotiate schedules with tact and diplomacy. At the end of the pack, you'll find short briefings on the recent work of the various groups.

We are seeking someone who will bring energy, skills and commitment to this exciting role, and in return, we want you to feel valued and engaged. We can offer:

- a 35-hour working week with flexible working hours and locations
- a positive culture for you to learn and grow in your role, including opportunities for international travel
- a vibrant, sociable office space close to London Bridge and Borough Market for those who want to be office-based or hybrid
- a personal pension plan
- an Employee Assistance Programme
- occupational sick pay
- 25 days holiday plus bank holidays

Our structure

BOARD OF TRUSTEES

Anna Hemnes President & Trustee
Paul Corris Chair & Trustee
Martin Wilkins Treasurer & Trustee
Anushka Patel Trustee
Paul Hassoun Trustee
Werner Seeger Trustee

Advisory Members

Bradley Maron President Elect

SCIENTIFIC & MEDICAL ADVISORY COUNCIL

Anna Hemnes Nashville, USA
Paul Corris Newcastle, UK
Laura Oppergard Harvard, USA
Jason Weatherald Alberta, Canada
Roham Zamanian Stanford, USA
Grazyna Kwapiszewska Graz, Austria
Catherine Simpson Baltimore, USA
Ardeschir Ghofrani Giessen, Germany
Jane Leopold Harvard, USA
Khodr Tello Giessen, Germany
Bradley Maron Baltimore, USA
Nick Morrell University of Cambridge, UK

STAFF TEAM

Karen Osborn CEO
Debs Driscoll Head of Comms & Marketing
Vacant Operations Manager
Katie Corris Admin Manager
Sarah Drumm Project Coordinator
Emily Lincoln Marketing Officer

Reporting

Supporting

Supporting

REGIONAL TASK FORCES

- India
- Latin America
- Saudi Association for PH (SAPH)
- Central Asia
- China
- South East Asia

INNOVATIVE DRUG DEVELOPMENT INITIATIVE (IDDI)

- Access to Care
- Challenges of Clinical Trial Design, Conduct & Endpoints
- Lung Transplantation in PH
- New Modalities & Technologies for PH & RHF
- Paediatric Clinical Trial Design & Endpoints
- Patient Engagement & Empowerment
- PH Group III
- Real World Evidence/ Real Work Data

DISEASE & SPECIALTY TASK FORCES

- Exercise
- High Altitude
- Imaging
- Infection in Pulmonary Vascular Disease (iPVD Consortium)
- International Consortium for Genetic Studies in PAH (PAH-ICON)
- Paediatric & Congenital Heart Disease

Job description

Job title: Project Coordinator

Responsible to: Operations Manager

Salary: £28,000 - £32,000 p.a. (FTE)

Hours & contract: Full time, 35 hours/week including occasional evening and weekend work. The role also involves international travel and short stays away from home (usually once or twice a year)

Location: Ideally hybrid with 1-2 days/week at our office in Bermondsey, London, but we're happy to consider either fully remote or fully office based.

Job purpose: To provide project and administrative support to our international workgroups (Workstreams and Task Forces), enabling them to successfully deliver complex academic and scientific workplans, surveys, webinars and academic papers.

Key tasks

- Schedule and manage virtual meetings across multiple time zones, develop and circulate agendas and meeting papers, take and distribute minutes, and follow up on action points.

- Aid the production of workgroup outputs, including:
  - set up complex online surveys, oversee testing, liaise with our Comms team to promote them, and collate, manipulate and distribute survey data
  - arrange pro bono translations of materials and surveys into different languages, using existing international contacts and finding new ones
  - proofread, edit and format academic papers for publication; liaise with Pulmonary Circulation Editors regarding fees and publication schedules for papers
  - support the planning, delivery and evaluation of webinars and e-learning in conjunction with our Comms team
  - schedule and support F2F meetings and scientific presentations at our international Congresses, Drug Discovery & Development Symposia, and other ad hoc meetings

- Maintain a diary of current and planned workgroup activities to ensure your work can be organised effectively to manage competing demands and that outputs are delivered on time and within budget

- Develop systems to ensure good communication and information flow between Workstreams and Task Forces, and with the PVRI team. Flag interesting workgroup developments, opportunities and challenges to colleagues, the Scientific & Medical Advisory Council (SMAC) and to our Board in a timely way

- Promote PVRI membership and support sponsorship and fundraising activities

- Support the engagement of underrepresented communities and sections of the PH workforce in workgroup activities, and take active steps to promote PVRI's EDI agenda across all areas of work

- Produce workstream reports, data and activity updates for colleagues, trustees and the SMAC, and for our website and publications

- Keep workgroup contact lists and CRM up to date

Person specification

The following skills, knowledge and attributes are required for this role

- Strong interpersonal skills and the ability to quickly develop positive and collaborative working relationships with diverse stakeholders
- Excellent verbal and written communication skills in English. The ability to write, edit and adapt complex scientific and academic information and to produce clear, accurate and accessible documents for a variety of audiences
- Excellent organisational and administrative skills: the ability to deal with complexity, scheduling, resource allocation, and manage competing priorities with tact and good humour delivering successfully to tight deadlines
- Proficient working knowledge of the Office 365 Suite and competence in the use of databases and survey tools (ideally including Survey Monkey)
- The desire and ability to develop a basic understanding of the key issues in pulmonary vascular disease
- A genuine commitment to our vision and values and to working in a way that promotes equality and inclusion
- Willingness to be flexible in response to the reasonable needs of the charity, to take on appropriate new responsibilities and be prepared to work flexible hours with occasional travel and overnight stays

We are a diverse and inclusive global organisation. We value lived experience, and we're genuinely open-minded about your background. If you think you have what it takes to make a real success of the role, we'd love to hear from you. If you have any questions or would like an informal chat about the role, please feel free to contact our CEO Karen Osborn at ko@pvrinstitute.org.

To apply

Please send your CV and statement, together with the Equalities Monitoring Form to Katie Corris at kc@pvrinstitute.org by 09:00 on Friday 28 March 2025. Applications will be judged against the criteria set out in the Person Specification, so please ensure that you reference these clearly in your supporting statement, and while we know that everyone uses AI in situations like this, we'd love to hear your own authentic voice!

In-person interviews are scheduled for Thursday 3 April 2025 at our London office, so please hold this date in your diary.

We look forward to hearing from you!

Meet our IDDI Workstreams and Task Forces

This section gives a quick overview of the recent activities of the different workgroups. We won't expect you to understand the detailed science behind the workgroups' agendas, but you will need be comfortable with academic and clinical language, and able to quickly pick up the broad themes.

IDDI Workstreams

Access to Care Workstream
This Workstream aims to identify and then address both the gaps in our knowledge and the variations in PH care across nations. For the last two years, their main focus has been a survey mapping inequities in access to PH care. Over 150 PH centres responded, providing data on the local challenges healthcare professionals face in diagnosing and treating PH patients. A paper based on the findings from the survey is in process, and next steps are a collaboration with PVRI's Regional Task Forces in low- and middle-income countries, exploring options for standardising right heart catheterisation and improving access to generic medications.

Lung Transplantation in PH Workstream
Since its inception in 2023, this Workstream has been addressing global access to transplants (LTX) across different allocation systems and transplant programmes. Members used a Delphi consensus process to identify the key issues in LTX, and presented their findings at scientific meetings. They've produced two academic papers on peri- and post-operative issues in LTX, and their latest project aims to help connect PAH centres with transplant programmes worldwide, to ensure that PH patients have better access to transplants. A recent patient-centred webinar 'Debunking myths about lung transplantation for PH – A webinar for patients and caregivers' featured presentations by clinicians and patients, and was one of the most popular PVRI webinars of 2024.

New Modalities & Technologies in PH & Right Heart Failure (RHF) Workstream
There are three strands to this Workstream: Monitoring of Diagnostic Device Technologies, Therapeutic Device Technologies, and Inhalation Drug Delivery Technologies. The group aims to change current thinking on how we identify, evaluate and adopt emerging device technologies for monitoring (diagnosis), treating (therapeutic) and targeted drug delivery (inhalation) in PH and RHF.

Paediatric Clinical Trial Design & Endpoints Workstream
We have a limited understanding of the disease-specific mechanisms underlying paediatric PVD, and this is further complicated by factors like the heterogeneity of conditions within PVD, treatments for paediatric patients being extrapolated from adult data, and a lack of well-informed guidelines and quality endpoints for assessing clinical courses and paediatric responses to therapy. This Workstream aims to change that by enhancing collaboration among care providers, basic and clinician scientists, experienced pharmaceutical leaders, regulatory experts, patients and their families and other advocates. The Workstream has several working groups, each tasked with solving a different challenge, and is active in publishing papers based on their work.

Meet our IDDI Workstreams and Task Forces

Challenges of Clinical Trial Design, Conduct, & Endpoints Workstream
This Workstream aims to provide solutions to complex questions and hot topics:

- What is the future of clinical trial design?
- How do we transform clinical endpoints into validated regulatory endpoints?
- How can we maximise outcomes for patients participating in these trials?

The group is currently taking a short break, and we plan to review and re-launch the work at our Drug Discover & Development Symposium in Amsterdam this June.

Patient Engagement & Empowerment Workstream
This group aims to understand the needs and perspectives of people living with PH, their views on their care and treatment, and their attitudes to participation in clinical research, and then share and act on these findings

In late 2023, the group launched the first-ever PH Global Patient Survey (PHGPS). With the help of international patient organisations, clinicians and patients, our Project Coordinator facilitated the production of the survey in 24 languages, and when it closed in September 2024, we'd received almost 4,000 responses from patients and carers in 88 countries. Presentations of early data were made at three major scientific meetings last year, and analysis will continue throughout 2025.

We hope this survey will be pivotal in shaping future research and enhancing healthcare to benefit patients globally. Given its potential, PVRI has committed to making this a permanent part of our work. With the help of our partners, we aim to run the survey every 4 years, so that as a PH community we can develop and learn from a truly rich body of data

We are now in the process of separating the GPS work from the PEE Workstream and launching a new independent GPS work group. This will allow the PEE to focus on other patient-centred challenges.

PH Group III Workstream
This Workstream aims to strengthen our understanding of PH due to lung diseases. The group holds monthly scientific discussions, often featuring focus lectures and journal club sessions. They aim to improve the care and daily life for PH Group III patients by:

- evaluating evidence and epidemiology
- defining different phenotypes and endophenotypes
- delineating innovative clinical trial design and endpoints
- identifying novel diagnostic, digital solutions, and treatment approaches

The group has published several consensus statements on ILD-PH, and the focus of the Workstream has moved from ILD-PH to COPD-PH publications on subjects including the significance of PH in COPD, pathogenesis and phenotypes, management and treatment combined with clinical trial design and endpoints.

Meet our IDDI Workstreams and Task Forces

Real World Evidence/Real World Data (RWE/RWD) Workstream
The goals of this Workstream are to strengthen the research community's understanding of RWE in PH to facilitate clinical research advances and ultimately improve patient care. They aim to:

- summarise the status of RWE in PH indications, and highlight opportunities for data generation
- engage academia, drug and device developers and regulators to develop key research questions that could be meaningfully addressed by RWE research
- to improve real-world patient care

In December 2023, the Workstream published a consensus statement 'Real-World Evidence to Advance Knowledge in PH: Status, Challenges, and Opportunities', and presented this at PVRI London 2024 and other meetings. The next step is to use a Delphi method to look at standardising data collected by global PH registries.

Disease and Specialty Task Forces

High Altitude Task Force
Studies indicate that factors linked to high altitude, including low oxygen levels, vasculopathy and metabolic abnormalities alongside genetic predispositions, collectively contribute to the onset and advancement of PH. This Task Force raises awareness and understanding of PH linked to high altitude, and organises scientific conferences in regions affected by high altitudes. Recent successes include the 7th International Leh Symposium held in Ladakh, India, in August 2024 and the 3rd International High Altitude Medicine and Research Symposium held in Naryn, Kyrgyz Republic, in September 2024, grant-aided by PVRI. The group is currently delivering its first ever series of PVRI High Altitude webinars.

Imaging Task Force
The Imaging Task Force's aims are to:

- harmonise imaging protocols to improve international clinical and research collaboration
- help to develop a network of international PH Imaging centres to allow dissemination of best practice
- facilitate a step change in how we use imaging and translate this into clinical practice
- disseminate current evidence for the use of imaging in the assessment of PVD in formats that will be accessible and educational

The Imaging Task Force meets at PVRI Annual Congresses and each meeting focuses on one or two primary themes, with presentations covering the gamut from basic research to clinically-focused talks. The meetings are, by design, very informal, with the express goal of maximising interactions among attendees. These have spawned countless discussions, research projects, and changes to clinical practice.

Meet our IDDI Workstreams and Task Forces

iPVD Consortium Task Force
The Consortium aims to enhance awareness about the role of infection in PVD, and foster research collaborations in infectious diseases covering basic science, translational and clinical aspects, aiming to better understand its mechanisms and global impact. The Consortium runs an occasional Virtual Symposium Webinar Series, hosted by PVRI. This is a global education programme highlighting the latest research on infections in PVD.

Paediatric & Congenital Heart Disease Task Force
This Task Force fosters global collaboration in paediatric PH, with a particular focus on maximising the potential of real-world data in PH registries worldwide. The mission is to bring people together to improve knowledge, encourage research and optimise the delivery of clinical care of neonates, children and adolescents with PVD wherever they live in the world.

Over the years, the number of members of the Task Force has grown to over 70, representing members from 17 countries. They group has published seven consensus documents and survey practice patterns in Pulmonary Circulation.

PAH-ICON: International Consortium for Genetic Studies in PAH Task Force
PAH-ICON is a network of centres that brings together research expertise and/or patient populations for collaborative genomic studies of PH. There are contributing centres in the UK, USA, Italy, Austria, Germany, Canada, Belgium, France, the Netherlands and Spain.

The goals of PAH-ICON are to:

- work towards a molecular classification of PAH
- provide a platform for whole genome/exome sequencing and analysis at centres with the capability/facilities/resources to undertake this
- share genetic data and analysis approaches
- publish definitive high-impact publications of these studies as a Consortium
- share best practices in ethics and feedback on pertinent genetic findings to patients and relatives

PAH-ICON's activities are organised into several active working groups, including deep phenotyping and data harmonisation, ClinGen, and scleroderma-PH, which is currently seeking funding to sequence samples from across the consortium.

Exercise Task Force
This is an international multi-specialty group including cardiologists and pulmonologists with expertise in exercise testing and interpretation. They meet rarely, but hope to publish a consensus statement on Exercise Testing.

Meet our IDDI Workstreams and Task Forces

Regional Task Forces

Central Asia Task Force
The Central Asia Task Force covers a large and sparsely populated region, and while it faces the common challenges of resourcing, their next meeting - in April 2025 in Bishkek, Kyrgyzstan - is being held as part of the Central Asian Respiratory Medicine Initiative.

China Task Force
For some time now, the China Task Force has been conducting the China Pulmonary Thromboembolism Registry Study (CURES-3), and to date over 19,000 PE patients and 1,500 CTEPH patients have been enrolled in the database. The Task Force was awarded grant support from the Ministry of Science and Technology, allowing for 20,000 new cases of PE and 1000 new cases of CTEPH to be enrolled into the study with 2 years of follow-up. They have also initiated a sub-study to evaluate the ICU treatment for high and intermediate PE (including the interventional and other reperfusion strategies). They hope to validate this therapy-stratified risk classification for guiding acute PE management in Chinese or East Asians.

India Task Force
The India Task Force has a strong track record of running webinars and conferences, and was instrumental in setting up India's first PH patient association. Its most recent scientific meeting for PVD doctors across India took place in Mumbai in December 2024, and the PVRI was delighted to provide support. Future plans include developing customised guidelines and protocols for treating PH in India.

Latin America Task Force
The Latin American Task Force held their 5th Paediatric & 2nd adult LATAM PH Symposium in Brazil in November 2024, supported by PVRI. The meeting addressed the latest advances in diagnosis and management of adult and paediatric PH and explored avenues to increase partnerships between adult and paediatric physicians to improve clinical outcomes and quality of life for PH patients across their entire lifespan.

Saudi Association for PH (SAPH) Task Force
SAPH is open to PH clinicians and academics from across the Eastern Mediterranean and Gulf states, and for many years has run highly successful international scientific meetings. In February 2025 SAPH held their 18th Annual Conference in Riyadh.

Southeast Asia
This is an informal group of about 52 members from Southeast Asia who share webinars on congenital heart disease / PH with other members. They are currently collating their practices in a paper on the different methods of PH management in the Asia Pacific region.

Our events take place around the world with our global membership - including recent events in Rio de Janeiro, Vienna, London, Bethesda, Athens, Lima, Barcelona & more!

Will you be joining us for our upcoming events in Amsterdam and Dublin?

PVRI